Quest #53 May 2002

Update on June 15, 2002 Symposium on Parralels Between Post-Polio Sequelae (PPS), Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia (FM)

Dr. Richard Bruno and Dr. Elizabeth Dowsett: Ambassadors for Canadians With ME/CFS, FM and PPS
Reported by Kate Andersen, M.Ed.

The house was full! Over 400 people attended the **National ME/FM Action Network's** 1st Annual Symposium on Parallels Between Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM) and Post-Polio Sequelae (PPS) on June 15, 2002 at the Holiday Inn Hotel and Suites Toronto-Markham, Ontario. Over half of the attendees had heard about the symposium through the Network's outreach, skillfully coordinated by Mary Ellen, Manager of Special Projects at the Network. The other half who registered at the door may have seen two interviews with Dr. Bruno on Toronto's CP24 CablePulse News, a 24 hour live news and information station with one of the best news ratings in Toronto.

Dr. Bruno was interviewed by David Onley, who is the "CityPulse" Science and Technology Specialist and a CablePulse24 Anchor. David is one of Canada's most articulate and well-informed television journalists and disability advocates. He is a polio survivor himself. Kudos to Dr. Bruno's Canadian publicist, David Leonard of HB Fenn, for achieving this publicity for Canadians with ME/CFS, FM and PPS.

The audience consisted of medical and legal professionals as well as patients. As the person privileged to introduce the renowned guest speakers, I found it remarkable to view this sea of people awaiting their words. Perhaps the attendees expected a dry presentation of research findings and a few intriguing similarities between ME/CFS, FM and PPS. If so, they would have been sorely disappointed. Both Drs. Bruno and Dowsett spoke with great humour and clarity - and immense compassion for patients. The parallels between ME/CFS, FM and PPS that they described were detailed, convincing and mind-boggling. Because this information has been somewhat hidden from both doctors and patients since the late 1980's, it may take some time for everyone to fully digest and appreciate its implications. However, one of the best ways to really appreciate what Drs. Bruno and Dowsett have to say is to read Dr. Bruno's new book, **The Polio Paradox: What You Need To Know**. A videotape of the whole symposium is also available from the Network. If you want to purchase any of these items, please see the order form flyer that has been inserted with this newsletter.

We remind our readers about the 2001 International Chronic Fatigue Syndrome Survey of Canadians, Americans and Britons, conducted by Dr. Bruno. We'll summarize this ground-breaking research once again. Dr. Bruno wondered if polio might be related to ME/CFS in baby boomers after a 1999 study by Leonard Jason found that half of the estimated 836,000 Americans with ME/CFS are at least 40 years old. Jason concluded that baby-boomers may be at greater risk for ME/CFS. Dr. Bruno thought that baby boomers' greater risk might be related to their having had an undiagnosed poliovirus infection in childhood, since they would not have been vaccinated against polio until at least 1955 when the Salk vaccine was distributed.

Dr. Bruno suspected the poliovirus as a cause of ME/CFS because of his twenty years of studying and treating polio survivors with Post-Polio Sequelae (PPS), the unexpected and often disabling symptoms -- overwhelming chronic fatigue, muscle weakness, muscle and joint pain, sleep disorders, heightened sensitivity to anesthesia, cold and pain, and difficulty swallowing and breathing -- that occur in paralytic and "non-paralytic" polio survivors about 35 years after the poliovirus attack.

"It has been known since 1947 that the poliovirus damages brain stem neurons that activate the brain - the 'brain activating system' that keeps the brain awake and focuses attention - whether or not poliovirus damages spinal cord neurons that move the muscles," says Bruno. "Some diagnosed with so called 'non-paralytic' polio were found to have severe damage to the brain activating system, and have severe fatigue today, even though they had no muscle paralysis."

Fifteen years of Post-Polio Institute research has found evidence of brain activating system damage in polio survivors with brain fatigue, including lesions on MRI of the brain, attention deficits on neuropsychologic testing, reduced levels of brain activating hormones, and brain wave slowing. "These abnormalities are identical to those in ME/CFS patients," says Bruno. "We believe that the poliovirus damaged brain activating neurons and causes the signs and symptoms of fatigue in both polio survivors and some baby boomers with ME/CFS."

To test this hypothesis, Americans, Britons and Canadians diagnosed with ME/CFS and FM were surveyed and asked if they'd had a childhood illness -- a fever that left them fatigued for several days, a stiff neck or muscle weakness -- in the years before the polio vaccine was distributed in 1955. Two-thirds of the 586 chronic fatigue patients who responded were born before 1955. They were on average 61 years old, just four years younger than polio survivors' average age in Dr. Bruno's previous International Surveys of over 3,000 polio survivors. Twenty percent of chronic fatigue patients born before 1955 were able to remember an illness with a fever, typically in 1947 when they were seven, which was the typical age of a polio patient in 1947.

"Just over one-third recall having had a stiff neck -- the 'red flag' symptom of polio -- about one-third were hospitalized and almost two-thirds remember having had muscle weakness," says Bruno. Remarkably the distribution of childhood illness cases in the baby boomers was nearly identical to the distribution of reported polio cases in the US and UK between 1935 and 1955. "What's more 90% of baby boomers with ME/CFS are women," says Bruno. "This is exactly the same percentage of women affected in the 1948 chronic fatigue epidemic in Iceland that was found to be caused by the Type II poliovirus." And ME/CFS patients who do remember a childhood illness are more affected than ME/CFS patients who did not remember an illness: baby boomers report more difficulty with concentration, thinking clearly, word finding and joint pain, have had more episodes of fainting, and are more likely to have sleep disturbed by abnormal breathing and muscle twitching."

"Our findings suggest that a relatively mild childhood illness occurring before polio vaccination began in 1955 -- likely caused by the poliovirus damaging the brain activating system -- sets the stage for mid-life symptoms that are identical to the 'brain fatigue' reported by polio survivors and patients with ME/CFS," says Bruno. "Dr. Bruno's research shows that there is very little, if any, difference between ME/CFS and PPS." Says Dr. Bruno’s collaborator, Dr. Elizabeth Dowsett.

"There is no question that neither the naturally occurring poliovirus nor the Sabin oral polio vaccine causes ME/CFS today," says Bruno. "But the possibility of a non-paralytic poliovirus infection in childhood causing chronic fatigue in middle-aged baby-boomers is a reason for hope."

Where does this hope come from? The Post-Polio Institute's research has found that conserving energy, daytime rests breaks, stopping activities before fatigue starts, and a higher-protein diet significantly reduce symptoms of fatigue in polio survivors and ME/CFS patients. In his new book, The Polio Paradox, Dr. Bruno describes all of his 20 years of research on PPS and ME/CFS and his successful fatigue treatment program.

"When baby boomers report symptoms of chronic fatigue, doctors need to ask if they had a childhood illness with a fever, stiff neck or muscle weakness that occurred during the polio epidemic years," says Bruno. "Whether or not patients recall a childhood illness, finding that over 50% of those surveyed had symptoms of abnormal nighttime breathing and that 80% had nighttime muscle twitching, requires that a sleep history be taken in anyone reporting chronic fatigue and that sleep studies be performed."

After treating nearly 3,000 patients with ME/CFS, Dr. Dowsett said, "There is very little, if any, difference between ME, CFS and PPS. In 1986, I began to read articles on PPS and have used them as guidelines for the management of ME/CFS patients ever since. This programme for treating ME/CFS has amply proved its worth."

Whether you are convinced about the parallels between ME/CFS, FMS and PPS or not, we know that our members, including physicians, agree THAT THE TIME IS LONG OVERDUE FOR CHANGE FOR CANADIANS with these conditions. We all know that there is strength in numbers, and given how much we have in common, it makes sense for Canadians to adopt Dr. Bruno's and Dr. Dowsett's strong recommendation that people with ME/CFS, FMS and PPS join forces for the purposes of advocacy and information-sharing. Such an initiative has already started in Europe. Dr. Bruno has reported that, in 2001, members of the Lincolnshire Polio Network joined with patients having nervous systems diseases -- including ME, Guillain-Barre Syndrome, multiple sclerosis, Parkinson's disease, spina bifida and myalgic encephalomyelitis -- in "The Neurological Alliance." He stated that the goal of The Neurological Alliance is to lobby the British National Health Service to recognize and provide quality care in local communities for everyone who has a neurological illness, including PPS. This brings us to more important news!

Following their lead, the **International Post-Polio Task Force** and the **Canadian National ME/FM Action Network** will be participating in **NAFTA** -- **The North American Fair Treatment Alliance** -- to join together the approximately 2.7 million American and Canadian polio survivors and ME/CFS and FM patients to lobby governments for education, benefits and services.

It seems that there are already at least two mottoes for NAFTA, emerging from Dr. Bruno's work:
1. "Now is the time for everyone with chronic fatigue and pain from any cause to take treatment into their own hands and to come to the aid of themselves."
2. "There is no more time to waste."

At the Network, we would add, now is the RIGHT time for Canadians to act, while the findings of the 2001 International Chronic Fatigue Survey of Canadians, Americans and Britons are hot off the press.

The June 15 Symposium was an enormous success. The National ME/FM Action Network is very grateful to Dr. Bruno and Dr. Dowsett for the time, skill, commitment, and caring they so generously gave to this event. Our thanks to Drs. Bruno and Dowsett is a promise to take what we have learned to bring about changes for people with ME/CFS and FM and PPS in Canada. Consequently, the Network's July 15th Agenda is now going to be presented by Lydia Neilson and Director Odile Gérin to Dr. Elizabeth Dickson, Senior Policy Advisor at the Canadian Institutes of Health Research. The agenda has been amended to be more specific and more comprehensive. This is what we are asking for:

1. An immediate information campaign to get the Canadian Clinical Diagnostic Protocol out to all Canadian family physicians, general practitioners, selected specialists, hospitals and clinics once it is published;
2. The establishment of a committee to develop an educational module for all Canadian medical schools and for continuing medical education/ board re-certification about PPS and ME/CFS, FM, starting with their common history and parallels and moving through diagnosis and treatment;
3. Better medical education in ME/CFS, FM and PPS from basic training through to continuing medical education for doctors who are already in practice;
4. Better medical practice in diagnosis and treatment of ME/CFS/FM and PPS;
5. Research funds earmarked for more research on these conditions, especially as they affect Canadians;
6. Support for the **National ME/FM Action Network** so that it can continue to operate and reach patients and doctors.

We promise to keep you posted on the outcomes of our talks with government. Stay tuned to the Network by reading the newsletter or checking out our web site regularly.

We especially wish to thank **Mary Ellen** for her tremendous work coordinating the symposium as well as all the volunteers who assisted her. We also would like to thank **David Leonard of HB Fenn and**

Company Ltd. (Publisher) for two free copies of **The Polio Paradox**, and the Holiday Inn in Markham, Ontario for a free room for our raffle.

Finally, we thank all the participants for their patience and fortitude in coping with ME/CFS, FM and PPS, whether it be in themselves, in a friend or family member, or in a patient.

SYMPOSIUM SPEAKERS: Elizabeth Dowsett, MBChB, Dip Bact., Honorary Consultant Microbiologist, Basildon and Thurrock Hospitals NHS Trust. Dr. Dowsett is an internationally-renowned expert on ME/CFS. She is the founder of the CFS Diagnostic and Management Service, Essex, England and has treated people with ME/CFS for forty years; and

Dr. Richard L. Bruno, **H.D., PH.D**. World's leading expert on Post-Polio Sequelae. He is the director of the International Center for Post-Polio Education and Research and Fatigue Management Programs at New Jersey's Englewood Hospital and Medical Center.

[**Kate Andersen, M.Ed**. has been the Youth Consultant for the **National ME/FM Action Network** for the past five years and was instrumental in bringing the 2001 International ME/CFS/FM/PPS Survey to the **National ME/FM Action Network**. Kate assisted with the organization of the symposium and introduced and thanked the guest speakers.]

Announcement: The **National ME/FM Action Network** is honoured to announce that we have appointed two new advisors:
Dr. Richard Bruno has accepted our invitation to serve as Special Advisor on Parallels Between Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS), Fibromyalgia (FM) and Post-Polio Sequelae (PPS).
Dr. Elizabeth Dowsett has accepted our invitation to serve as Honorary International Advisor on Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS).

FIBROMYALGIA – A Syndrome of Disturbed Physiology

By: W.J. Reynolds, MD, FRCPC, Rheumatologist – Associate Professor

Fibromyalgia is a common disorder that has attracted increasing interest for investigators over the past decade. Patients with fibromyalgia experience a wide variety of symptoms that relate to pain, sleep deprivation and stress. Although there have been numerous studies of underlying basic mechanisms of the disorder, the pathogenesis of fibromyalgia is still not understood. Recent research, however, has demonstrated significant physiological disturbances that may explain many of the clinical features of fibromyalgia.

The major features of fibromyalgia are generalized pain throughout the trunk and limbs and marked sensitivity. The physician documents the presence of sensitivity by the demonstration of painful tender points, but the patient also recognizes sensitivity to many environmental influences such as bright lights, loud noises or various odors.

It has been considered that the pain and particularly the sensitivity that patients experience relate to physiological changes in the central nervous system. A clinical observation in keeping with this is that frequently patients recognize that one side of their body is more painful than the other and this, of course, suggests the role of central neurological mechanisms. Physiological changes that have been recognized for several years include the presence of elevated levels of substance P, a pain peptide, in the spinal fluid and low levels of serotonin in the spinal fluid and in the serum. Serotonin is recognized to play a role in pain control and to influence sleep. Other abnormalities related to central neurological function are changes in blood flow patterns in areas of the brain that process pain signals. All of these findings have been demonstrated in different research centres and may be fairly specific for the disorder of fibromyalgia. However, an integrated understanding of how these relate to the symptoms that patients experience is not yet understood adequately.

Although there are central mechanisms involved in the pain symptoms of fibromyalgia, a prominent component of pain is local muscle pains, i.e. myofascial pains. These are localized severe muscle pains that affect trunk and limb muscles, but may also be a frequent cause of headaches, of jaw pain, and of chest pains. It is not uncommon that patients with fibromyalgia experience severe chest pain, but are found to have no evidence of underlying heart disease. The pain arises from an electrically activated trigger point in the muscles or tissues, and this gives rise to a spread of pain down a limb or across the trunk or in other patterns. Patients recognize that myofascial pains are frequently brought on by performing strenuous physical activities, by maintaining prolonged postures such as sitting for long periods, and generally recognize that stress is very prominent in accentuating myofascial pain.

For many years sleep difficulties have been recognized to be associated with the disorder of fibromyalgia. Sleep in fibromyalgia is generally very superficial and is almost always non-restorative. Patients frequently have difficulties in falling asleep, waken frequently throughout the night and generally feel unrested when they arise in the morning. This non-restorative sleep pattern gives rise to fatigue that often becomes significant by midday. Patients as well recognize some mood symptoms, i.e. feeling depressed, irritable and anxious. Finally a prominent consequence of a non-restorative sleep is difficulties with short-term memory and concentration.

Sleep studies generally confirm the significant difficulties in both initiating and maintaining sleep. However, a very common finding is the presence of an alpha EEG arousal rhythm, first recognized to be associated with fibromyalgia about twenty-five years also. It is now considered to be very characteristic of the sleep disturbance of fibromyalgia.

The above physiological changes in pain control mechanism and in sleep mechanisms have been recognized for several years. More recent studies have focussed on the role of the stress mechanisms of the body in fibromyalgia, and these findings may provide a better blueprint for an understanding of fibromyalgia.

Several studies of the stress glands of the body, (hypothalamus, pituitary and adrenal), have demonstrated some evidence of underfunctioning of these glands. There are frequently low levels of corticosteroid secretion, but more prominently there tends to be a delayed and often inadequate response of these glands to a stimulus. It is probable that the major hypofunction is at the level of the controlling gland, i.e. the hypothalamus, and it is possible that this may relate to the large amounts of substance P in the spinal fluid. The clinical understanding of these findings, however, remains to be determined and it is unclear as to how these findings can be translated into clinical symptoms.

The other arm of the stress system is the autonomic nervous system, and this is comprised of two divisions, i.e. sympathetic and parasympathetic systems. The autonomic system is responsible for maintenance of cardiac, cardiovascular, respiratory, bowel and bladder functions, among others in our bodies.

Several centres have used a new investigation technique of the autonomic system, i.e. spectral analysis. The length of each heartbeat is recorded over a period of time, perhaps twenty-four hours of the day, and then mathematically the contribution of either the sympathetic or parasympathetic systems at any one time can be calculated. The studies demonstrate that there is a major imbalance in this system with a marked predominance of the sympathetic side present throughout the twenty-four hours of the day. This observation helps to explain the frequency of autonomic symptoms experienced by patients with fibromyalgia, i.e. sensations of tingling or numbness, sensations of swelling, and frequent colour changes in the skin, i.e. blue and white patterns in the fingers when exposed to cold or red blotchy patterns. It could explain the common sensations of feeling hot or cold associated with marked perspiring, the frequent occurrences of runs of rapid heartbeats and the unsteadiness and light-headedness many patients experience. The increased sympathetic drive also appears to explain the sleep disturbance, i.e. the presence of the EEG arousal rhythm, and as well the recognized sensitivity of myofascial pains to any form of stress. It has been shown that the sympathetic system may activate the trigger points that are responsible for myofascial pains.

Patients with fibromyalgia almost always recognize that they are markedly sensitive to any form of stress, and this relationship to stress is supported by the physiological abnormalities of the stress system that are being demonstrated. It is still not understood how the central neurological dysfunction and the stress dysfunction relate to each other, but this will doubtless become clearer with future studies.

In order to cope with their symptoms, patients with fibromyalgia recognize that they have to decrease their activities to a level that allows them to manage their symptoms more effectively. This, of course, is frequently very difficult to achieve. Certainly the use of appropriate medications and treatments such as massage are helpful, but only to a degree. It has long been recognized that stress system dysfunction may be influenced by exercise, and this is a rational for the advice to patients to perform daily exercise routines. In time, patients generally recognize that the performing of modest exercise on a regular basis has a beneficial effect on the intensity of symptoms.

Overall we may be developing some further understanding of the disorder of fibromyalgia, as outlined above, and with a better understanding we will hopefully be able to manage the disorder of fibromyalgia more effectively.

ACCESSING JUSTICE - Pension Appeals Board Denies Minister’s Request for Independent Psychiatric Examination for CPP Claimant with Fibromyalgia

By: Hugh R. Scher

It is generally understood by people with Fibromyalgia and Chronic Fatigue Syndrome and all claimants who apply for Canada Pension Plan Disability Pension that the Minister has a very broad discretion to compel claimants to attend Independent Medical Examinations as required by the Minister. The CPP legislation and regulations are very broad in this regard granting the Minister a very wide discretion to require claimants to attend Independent Medical Examinations. That said, a recent Pension Appeals Board ruling suggests that the Minister’s discretion is not unlimited with respect to compelling claimants to attend IME’s. In the case of The Minister of Human Resources Development Canada v. Pamela Dubowec (2000) the Chairman of the Pension Appeals Board agreed with our submission on behalf of Ms. Dubowec that to order such an independent psychiatric examination at this time would be unfair to the Applicant, Pamela Dubowec. As such, the application by the Minister for a further medical examination was denied. The circumstances giving rise to this case are as follows:

Ms. Dubowec applied for a Canada Pension Plan Disability Pension in December, 1995. Her application was denied by the Minister. After appealing to a Review Tribunal, Ms. Dubowec was granted a disability pension in July, 1998. At this time, the Minister appealed the decision of the Review Tribunal to the Pension Appeals Board claiming that Ms. Dubowec did not meet the definition of disability under the Act. Prior to the hearing before the Review Tribunal, Ms. Dubowec had undergone an IME with the Minister’s chosen specialist, an Internist. Ms. Dubowec had in fact seen this same internist on two (2) occasions prior to the Review Tribunal hearing. At no time prior to the Review Tribunal hearing or in the course of adjudicating her claim did the Minister request a psychiatric assessment. Only after a Review Tribunal granted Ms. Dubowec’s application for a CPP disability pension did the Minister seek to obtain an independent psychiatric assessment of Ms. Dubowec.

Ms. Dubowec has Fibromyalgia with primary symptoms of chronic pain and fatigue. While she has experienced depression periodically on account of her chronic illness, she is not clinically depressed. As such, the Minister’s request for a psychiatric assessment is based on the Minister’s mischaracterization of Fibromyalgia as a psychiatric disorder rather than a chronic physical disability.

Prior to the Review Tribunal hearing, Ms. Dubowec had submitted medical reports from her family physician as well as from psychiatrists and sleep experts, Dr. Harvey Moldofsky and Adam Blackman. As such, the Minister was aware of previous psychiatric assessments undergone by Ms. Dubowec prior to the Review Tribunal hearing. Despite this knowledge and despite the IME to which Ms. Dubowec was subjected by the Minister, the Minister made no effort to request a psychiatric assessment of Ms. Dubowec in order to assess her condition, or to adduce evidence before the Review Tribunal. It was our submission and the Chair of the Board agreed that the Minister's application for a psychiatric assessment, coming as it does after the decision of the Review Tribunal, is in effect an attempt to obtain new evidence which the Minster may adduce at the appeal.

We submitted, and the Chair of the Board agreed, that the Minister had ample opportunity to request an independent psychiatric examination prior to the hearing before the Review Tribunal but did not do so. By the exercise of due diligence, such an examination could have been held and such new evidence obtained. We submitted and the Chair of the Board agreed that to order such an independent psychiatric examination at this time would be unfair to Ms. Dubowec.

The ruling by the Pension Appeals Board demonstrates that the Minister's exercise of discretion to compel claimants to attend independent medical examinations must be exercised fairly, in a timely way, and in a non-discriminatory fashion, consistent with the principles of fairness, natural justice and equality under the Charter of Rights and Freedoms.

At this time, the Minister has appealed to the Federal Court of Appeal for a review of the decision of the Chairman of Pension Appeals Board. *This hearing is scheduled to take place toward the end of February, 2002.* The Minister will be arguing that the broad language in the Canada Pension Plan legislation and regulations enables it to compel an independent psychiatric examination.

It will be our position that the decision of the Pension Appeals Board Chair was reasonable and lawful having regard to the timing of the Minister's request to compel a psychiatric assessment of Ms. Dubowec, the number of medical examinations to which Ms. Dubowec has already been subjected, the marginal relevance of the evidence sought by the Minister, the onus upon Ms. Dubowec to prove her disability before the Pension Appeals Board and the options available to the Minister to have an independent expert review all medical documents on file to assist her to determine Ms. Dubowec's medical condition and psychiatric state. Moreover, it is our position that the Pension Appeals Board Chair interpreted the Act and regulations in a manner consistent with the principles of natural justice, fairness and Ms. Dubowec's charter equality guarantee under s. 15(1) of the Charter of Rights and Freedoms.

While each case must be looked at individually, this ruling suggests that it is not appropriate in every case for the Minister to compel claimants to attend IME's. Consequently, claimants should be mindful of the circumstances under which IME's are sought, the timing of the exam, the relevance of the information sought and the fairness of the request. Advice of physicians and counsel should be sought before submitting to such assessments.

Note on Author: Hugh Scher is a partner in the law firm of Scher and De Angelis where he practices civil litigation and administrative law with a focus on insurance, employment, and human rights law especially in the area of disability rights. He also serves as counsel to the National ME/FM Action Network and Ontario Fibromyalgia Society and has represented dozens of individuals with Fibromyalgia and Chronic Fatigue Syndrome in disputes with long-term disability insurers, the Canada Pension Plan, employers and Revenue Canada.

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INDEPENDENT MEDICAL EXAMINATION – UPDATE

By: Mary Ellen, Special Projects Manager

The National ME/FM Action Network is urging all people who have attended an independent medical examination, functional capacities evaluation or any other form of assessment at the request of an insurance company or Canada Pension Plan (CPP) to act now by doing the following:
1. Fill out our 7 question, confidential, independent medical examination Registry Submission Form so that the names of the doctors and healthcare professionals who evaluated you can be on record; AND
2. If you feel that your evaluation was biased,

(Did the evaluator believe that people can be disabled to the point where they are unable to work? Did the evaluator have the latest scientifically-based research about the organic nature of your illness? Does your evaluator treat patients disabled with your illness or only do assessments for insurance companies?) OR, if you feel that your evaluator was unqualified to do the evaluation, (Was he/she a specialist in an area that is appropriate to your illness? Does the regulating body, such as the College of Physicians and Surgeons or College of Psychologists approve of this doctor doing assessments in this area of specialty?) OR, if you feel that you were treated disrespectfully, (such as being accused of malingering or being called any other names of disrespect such as "manipulative", "deceptive", "cunning" or spoken to in an abusive tone or with abusive language) OR, improperly threatened to comply with the assessment,

We urge you to write a short letter of complaint to the regulatory body in your province and send a cc. National ME/FM Action Network

There is no more time to waste. Colleges of Physicians and Surgeons, Colleges of Psychologists, and Colleges of Physiotherapists, etc., are now looking into the issue of a fair IME. Please send your letter of complaint. Your letter WILL make a difference. We must keep up the pressure to ensure better treatment for disabled people who must undergo these assessments. Please help yourself and others by writing your letter.

To receive a copy or copies of the simple, confidential, 7 question Registry Submission Form, please Contact: **Mary Ellen**, Manager of Special Projects, Phone or fax: **(905) 831-4744** Mail: **P.O. Box 66172, Town Center Postal Outlet, 1355 Kingston Rd., Pickering, ON., L1V 6P7** Email**:** **marye@pathcom.com** - Or download the Form from our web site at **www3.sympatico.ca/me-fm.action/medexam.html**

NATIONAL DOCTORS' ROSTER – ADDITION

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BOOKS/REPORTS/VIDEOS ETC.

*THE POLIO PARADOX: What you need to know – By: Richard L. Bruno, H.D., PH.D. Uncovering the Hidden History of Polio to Understand and Treat "Post-Polio Syndrome" and

Chronic Fatigue – Cost: **$36.00 plus** Shipping & Handling – **Canada: $7.00** - **International: $10.00**

*Video on National ME/FM Action Network's 1st Annual Symposium on Parallels Between Post-Polio Sequelae, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Fibromyalgia – June 15, 2002 - Cost: **$30.00** (includes S & H)

OUR WORLD: MY NEW ME/FM EXERCISE PROGRAM

I thought I would let you, my friends, in on a little secret I've found for building my arm and shoulder muscles. You might wish to adopt this regimen - 3 days a week works well. I start by standing outside behind the house and, with a 5 pound potato sack in each hand, extend my arms straight out to my sides and hold them there as long as I can.

After a few weeks I moved up to 10 pound potato sacks, then 50 pound potato sacks and finally I got to where I could lift a 100 pound potato sack in each hand and hold my arms straight out for more than a full minute!

Next, I started putting a few potatoes in the sacks, but I would caution you not to overdo it at this level. (author unknown)

"QUEST COLLECTION" BOOK - FIVE YEARS: By popular request, **the National ME/FM Action Network** has published an easy to read book consisting of a **collection** of important articles which have appeared in our **'QUEST'** newsletters over the years. For easy reference, these articles have been grouped into sections, according to their focus i.e. medical, legal etc. We have kept the **cost** of the book to a minimum at **$20.00** each which includes shipping and printing. Please make **your cheque payable to the National ME/FM Action Network** and let us know how many copies you would like.

TEACH-ME - Sourcebook for Teachers. We are proud to announce that **our Sourcebook for Teachers**, an educational resource book full of information and teaching strategies for teachers and parents of children and youth who have ME/CFS and/or FM and is now available in hard copy **– Cost $22.00 which includes shipping and handling. Discount on Bulk Orders. See Order Form flyer with this newsletter.**

LEGAL/RESEARCH PACKAGE - **Medical** and **Legal** Information on ME/CFS and/or FM, a resource for lawyers, advocates, doctors and patients. Please make **cheque payable to Marj van de Sande** in the amount of **$25.00** (our Director of Education) to cover photocopying, postage charges etc., **151 Arbour Ridge Circle NW, Calgary, AB T3G 3V9 - Tel/Fax: (403) 547-8799 - E-mail:** vandesam@cadvision.com

MEMBERSHIP: $25.00 per year which includes bi-monthly newsletters – Please make cheque payable to:

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